

DATA DEVELOPMENT SUBCOMMITTEE DRAFT MINUTES
July 09, 2019 – 4:00 PM
Margaret M. O'Neill Bldg. 2nd Floor Conference Room, Dover, DE

QUORUM MET – 3 OF 5

PRESENT: Karen **McGloughlin**, **CHAIR**, Director of Women's Health; Christine **Applegate**, RN Navigator, Bayhealth; Andrew **Burdan**, Brain Injury Advocate/Support Group; Nicholas **Duko**, Program Manager, LTSS, BCBS Highmark Health Options; and Dee **Rivard**, SCPD Support.

RESIGNED: Thomas **Cairo**, Bayhealth Neurosurgery;

GUESTS: (Not able to vote or count toward quorum)

IN-PERSON – John McNeal, Director, State Council for Persons with Disabilities; Kyle Hodges, Legislative Policy, State Council for Persons with Disabilities; Randall J. Farmer, COO DHIN website: <https://dhin.org/>

TELECONFERENCE PARTICIPANTS: TerriLynn Palmer, Director of Data Analytics, Delaware Health Information Network (DHIN);

CALL TO ORDER

Karen called the meeting to order at 3:10 p.m., thanking Mr. Farmer and Ms. Palmer from Delaware Health Information Network for participating in today's meeting.

DHIN Update

HB No. 230

COO Randy Farmer was excited about the great success this subcommittee had in getting HB No. 230 passed this session enabling access for the State Council for Persons with Disabilities to the DHIN claims data.

- HB 230 added the SCPD as one of the sanctioned to access the DHIN data along with the 4 original organizations sanctioned by SB
- Randy stated that the DHIN needs to understand what types of insights the SCPD/Brain Injury Committee (BIC) wants in order for the DHIN staff to do refinements for inclusion and exclusion criteria. The DHIN will provide the output and then the DDS Work Group will need to decide whether or not the BIC requires any refinements to the data.
- Randy is interested to know what types of insights the DDS members obtained from working together. Scott Perkins, Esquire from the DHIN will walk Kyle through the initiative.

- As part of that process, one of the decisions that need to be made is how many people will have access to the data.
 - John advised data access is going to be limited to the SCPD staff in order to ensure who has data access and that it is not being shared in a way that is not permitted.
 - Randy Farmer stated that the DHIN typically recommends a single point of contact.
 - John and Karen both recommended Dee as the single point of contact.

REGULATION DEVELOPMENT ADDRESSING SCPD DATA SHARING

Karen shared that the Archives group has a very formal process in place authorizing state employees to create or destroy state records and she believes that the SCPD/BIC also needs a formal written process in place.

- TerriLynn Palmer briefed the DDS members on the process of how the DHIN manages their data access advising that it incorporates the Department of Technology & Information (DTI) Data Agreement.
- The general process includes a small workgroup from the BIC Team that will need to complete an application and business process in order to ensure that we have all of the checks and balances in place.
- The business requirement document deals more with the data element and how the DHIN will aggregate the data or not aggregate the data. As it is right now only DHIN staff have access to log-in to the DHIN database. This means that someone from the DHIN staff will pull the requested data in order to provide the SCPD/BIC access to the data.
- TerriLynn will set the working group meeting by sending a request to Dee. Initially this working group will need to meet at least once per week for 3 to 4 weeks until all of the SCPD/BIC needs are hacked out along with the progress of the process. She assured everyone that she will start simple and get some data so the DDS members will have something to work with. However, there are some documents to gather first.
- Randy advised that there is a Data Use Agreement that John on behalf of the SCPD needs to execute with the DHIN. Randy stated that Scott will shepherd this process with Kyle and John. He advised that the DHIN can start with the same language as used by the other 4 agencies who have data access.

- TerriLynn stated that Scott, Kyle and John's process will not hold up the DHIN/DDS Working Group although the DHIN cannot actually exchange data with the SCPD/BIC until John and Kyle are satisfied with the Data Use Agreement and John signs it.
 - TerriLynn will start by sending a bunch of the documents to share with DDS members. Data dictionary, access applications used for organizations that have to access the data to gather necessary data; business requirements document, along with other items, the fee schedule. We will work through the pieces that we need to work through. Randy stated that this is referencing claims data. We are hoping that this will be addressed through their Sunset process.
- John advised that the SCPD provides oversight for personal attendants and that with full access for all of the DHIN claims data it will greatly assist the Council.
 - Randy Farmer stated that the DHIN has full intention of adding the clinical data access through their Sunset process.
 - Karen inquired if the DDS members could get an idea of what other data is available to compare our request to. She doesn't know how broad DHIN's scope is. For example, the Division of Public Health has done studies to know that women who are heads of household have lower incomes and have lower health outcomes. There may be an opportunity for the DHIN to take some sort of cross pollination in the background of their data in order to have social determinant information with insights on the claims data for an expanded point of view. Less physical activity leads to poorer health outcomes.
 - Randy responded that in terms of pots of data the DHIN is the claims and clinical data. DHIN has some data through 2013 and commercial data goes through 2015. DHIN has an absolute ton of health related data. The opportunities are infinite in terms of what can be garnered out of that by compiling that with other data. This is going to be FUN!
- Data Work Group - Dee will remain the POC for this working group. TerriLynn should copy Scott and Randy when she sends the DUA, Scott may follow up with ones that have the State components.
- John told a story about a phone call for the DHIN to participate in a focus group. John ended up being a part of the focus group through a wrong number call.

- At this time, Randy and Terry left the meeting.

REVIEW & APPROVAL OF PAST MINUTES

- Karen called for review and approval of the May 28 meeting minutes allowing members time to review the minutes prior to discussion and vote.
 - Nick Duko noted a correction to the last page stating that the adjournment time was 4:45 not 3:45. Nick made a motion to approve as amended, that Christine seconded and the DDS members present unanimously approved.
 - Karen called for review and approval of the 6/10 Meeting Notes allowing members time to review the notes prior to discussion and vote.
 - Kyle advised that on page 4 under burger dot 2 that Representative Andria Bennett's name is spelled with an "i" not an "e."
 - Christine made a motion to approve 06/10 notes as amended. Andrew seconded the motion and DDS members in attendance unanimously approved the notes as amended.
- Karen noted that this subcommittee needs to take baby steps with regards to the DHIN data portal. She advised that the Division of Public Health database portal only has 10 diseases populated at this time. It is going to be wonderful once it is fully populated. Can we now extrapolate how many persons with disabilities received immunizations? Unfortunately, data is not collected around whether or not someone identifies as a person with a disability. Everyone keeps getting stuck on the definition of disability. There are multiple different definitions and this is where agencies collecting data frequently run into issues. Many people don't self-identify. It harkens back to the late 60s when we first started collecting racial data. One of the areas that is most logical is the ongoing issue around the wearing of helmets and prevention issues surrounding the severity of bicycle and motorcycle injuries when helmets are not worn. The ability to collect real data on Delawareans with greatly assist services, education, and prevention efforts. As an example, persons with disabilities have a higher percentage of diabetes. There are just a myriad of things that contribute to diabetes; however, until you collect the data you just don't know.

OLD BUSINESS

- Karen brought up the need during the main Brain Injury Committee (BIC) meeting that the DDS members need to obtain a better understanding of what BIC members want or need to do with the TBI data. Karen inquired as to who is talented with surveys? There are ways to pull information out of people without causing confusion as to the amount of information being requested. As of this meeting, no one from the BIC responded to our verbal requests

for information. If we can develop a 5 question survey we might be able to get the necessary information from the BIC members.

NEW BUSINESS

- Looking for TBI claims data that is inclusive of the information that Terri and Randy provided, that answers the questions the BIC members are asking, and that gives the SCPD/BIC the most relevant information necessary for applying for federal grants. This information should include dates of services, types of service, injury by ICD-10 codes, origin of injury, and origin of service by zip-codes. In other words the top 10 ways that the SCPD/BIC members plan to utilize the traumatic brain injury data from the DHIN.
- Karen suggested that the best way to accomplish this might include providing a survey for the BIC members to complete instead of just asking them to tell us how they plan to use the data because that question is too broad to obtain specific information. Committee members agreed that a survey would help to focus the BIC members in order to allow the DDS members to obtain the required information that the DHIN needs to query their data. Karen advised that the DDS members need to stay in for the exponential growth while limiting the first data request to something simple. Once the DDS members have a final somewhat defined report they can then start to add additional variables. Perhaps we could contract with the University of Delaware to assist with variables and analysis. The DDS members can always add additional questions at a later date. This survey should go out to only the BIC members first.
- Karen requested that Dee first assemble the DDS TBI Data Survey in MS Word format to share with the DDS members for review prior to entering the questions into Survey Monkey and submitting it to the entire BIC membership.

TBI Data Needs Survey

Please respond to the following questions by answering them from the perspective of within your agency, organization, or area of expertise.

Funding – With the understanding that BIC members want to use the availability of the DHIN data to obtain additional funding in order to increase the BIC activities.

1. What funding sources would you go after?
2. What type of funding do you think that the Brain Injury Committee should seek?
3. What specifically would you do with the money once you received it?

4. What specific types or categories of data do you need to inform that project?

Research – Think about the types of research that you, your agency, or organization are already doing or could do if you had access to TBI data for Delaware.

1. Who would you go to for research funding?
2. What kinds of research would you like to see happen in Delaware?
3. Who would you have on your team doing this research? E.g. people that you would include.
4. Who would your partners be? E.g. What organizations would you partner with on your research project?

Prevention – Think about areas of prevention that are needed as they relate to traumatic brain injuries.

1. How will the data will inform prevention services?
2. Who would you go to?
3. How would you increase prevention and education services in Delaware based on the data received?
4. What specific types of areas do you want to see more of a prevention focus?
5. What kinds of data do we need to request from the DHIN in order to support that?
E.g. Policies and Legislation

Services – Think about the types of services that your agency or organization provides or could provide for traumatic brain injury survivors.

1. What do you want to improve?
2. What areas do you want to investigate improving?
3. What data sources do we need to focus on in order to look at those areas? E.g. Radiological services for brain bleeds, length of time between injury and date of radiological services.

Thoughts – Do you have any additional thoughts that you would like to share with the DDS members?

1. Please share any additional thoughts or insights.
- People have to consider where they choose to live and the consequences of their choice including their physical well-being, projected physical well-being, availability of transportation and availability of services. Having knowledge results in a change in power.

You may find over time that you choose to move to an area with a higher density of population and services.

Questions?

- When Terri sits down and starts going over the data Christine mentioned that she would like to be part of it and volunteered to shepherd the Working Group effort along with TerriLynn from the DHIN. Eventually we are going to get into the weeds on this.
- TerriLynn advised that the first meeting is very technical.
 - John advised that he and Kyle will tag team attending meetings.
- DDS members should look at what kind of data they use and the structures used for obtaining data. Even if it is just a form. Who are we going to give this data to if anyone? If you have a form for data requests it will make sharing requests easier. The BIC has a responsibility for education and sharing. Perhaps someone from the Prevention & Outreach (P & O) Subcommittee should attend the working group sessions.
 - Since Christine is currently one of the Sussex County P & O Subcommittee members who is now going to shepherd the working group meetings with TerriLynn from DHIN we need to apprise the P & O Chair that they tentatively need another member for Sussex County to replace her.
 - Requests for data will go through an approval of data requests process prior to submission to the SCPD point-of-contact who will in turn request the data from the DHIN.
 - Perhaps one of the newer BIC members might want to join the DDS or the P & O Subcommittee.
- At some point Karen would like the DDS members to move forward towards creating some kind of written document as to what the SCPD staff, the DDS member and the Prevention and Outreach Subcommittee responsibilities are in addition to determining what a request for data needs to include.
- Andrew inquired about federal legislation he heard about that was initially proposed by President Clinton to create a TBI database that received approval and then renewal by President Bush and President Obama.
 - Karen responded that what he was talking about was non-funded legislation that the Centers for Disease Control (CDC) came out with a rebuttal to because it was not an

effective way to handle the issue and needs. Because of how far the CDC and data sharing in general has come the CDC wants all of the data to feed into them. It is just so costly for states to develop and maintain individual TBI Registries because individual registries require specific reporting agencies, analysts to analyze the data, and staff to manage the database and perform queries.

- This subcommittee needs to remember that we still do not know if the SCPD/BIC will have to pay to obtain the DHIN clinical data. Karen hopes that it is going to go the same way as the claims data; however, she is aware that the DHIN has not yet stood up their whole structure.
- Nick Duko recommended giving the **TBI Data Needs Survey** to the BIC members during a meeting after having sent it electronically in order to hopefully obtain responses directly from the BIC members in attendance.
 - John strongly encouraged the in-person message while Karen works in a different light and needs to have the survey open on her desktop computer and visible at work to give her the flexibility of returning numerous times to the Survey questions in order to add additional details.
 - When the BIC Agenda is sent out. The DDS members will request sufficient time for the BIC members to come to the meeting prepared to provide survey responses during the meeting.

ANNOUNCEMENTS

- Tom Cairo emailed Karen his resignation from the DDS noting his full-faith in Christine Applegate's ability and her being fully involved with the DDS.
- Committee members in attendance that Tom's resignation will require the election of a Vice-Chair at our next meeting since Christine agreed to shepherd the working group.
- Karen envisions the BIC Retreat having breakout sessions for each of the BIC Subcommittees.

NEXT STEPS – 07/09/19 Meeting

- Coordinate, approve, and disseminate the **TBI Data Needs Survey**.
- Request addition of time at the next BIC meeting for members to complete and turn-in survey responses.
- Schedule

ADJOURNMENT

- Andrew made a motion to adjourn the meeting that Christine Applegate seconded. Karen called for discussion and hearing none, voting subcommittee members present unanimously approved the motion to adjourn.
- With no further business to discuss the meeting adjourned at 4:15 p.m.

NEXT MEETING

Dee will work to schedule the next DDS meeting at a time and location convenient for all members.

Next Meeting

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We really need to set a regularly recurring meeting date and time.